explained—title of a *concertante* by J S Bach's contemporary Jan Dismas Zelenka. It has recently been recorded on a Teldec compact disc.

With so much dual talent it is hardly surprising to learn that at the 1932 meeting of the Canadian Medical Association a Dr Forde McLoughlin conducted his own work, Influenza, A Tone Poem. Could any Canadian reader tell us more about this occasion or procure a copy? As recently as 1948 Dr Herman M Parris produced, with the Doctors' Orchestral Society of New York, a 10 movement orchestral suite, The Hospital, with movements entitled Anaesthesia (presto), A Nurse (allegro amabile), and a Pre-operation Prayer. Does the event figure in the society's annals?

#### Blow by blow description

But there is nothing new. The French viol virtuoso and composer Marin Marais celebrated an "operation for the stone" with his Lithotomy Sonata for viola da gamba and harpsichord, which gives a blow by blow musical description of the operation together with a running commentary:

The Patient mounts the Operating Table He takes fright, and tries to get down again. His limbs are restrained with silken Cords. The Incision.

The Blood Flows

The Cords are untied and the Patient is put to Bed to recover. Dance of Relief and Rejoicing.

The dance of relief and rejoicing was presumably performed by surgeon and staff, not the patient. Samuel Pepys would have loved it, for in 1658 (when Marais was a child) he suffered an operation for the removal of a kidney stone and thereafter celebrated its successful outcome with an annual "stone feast."

Victorian doctors and their patients, pharmacists, and patent medicine manufacturers often figured in ballads and music hall songs, which from the mid-nineteenth century, thanks to cheap colour lithography, resulted in a great abundance of delightfully illustrated sheet music. Although sex was still taboo suggestiveness was permitted, and songs about doctors, ailments, cures, remedies, and popular health



"The Quack's Song"

crazes were always popular. They were sometimes issued as barely disguised "commercials"—for example, Phrenology—a New Song Dedicated to the Heads of the Universities, Public Schools and Private Families, Ipecacuanha, Morrison's Pills, or Mrs Winslow's Soothing Syrup, which the young Edward Elgar immortalised in one of his works—a veritable procession of musicomedical social history. Some songs even managed to offer primitive health education with the help of music, like The Hygeia Waltz and The Death of King Dirt—a Domestic Revolution, being a parody on the popular ballad, The Death of Nelson.

# "Human guinea pigs"—a history

### M H Pappworth

In 1962 I was approached by the editor of *Twentieth Century* (a now defunct literary magazine) to contribute to a special number entitled "Doctors in the Sixties." My article, called "Human Guinea Pigs: A Warning" appeared in the autumn of 1962, describing 14 experiments in lay language; no names were named and journal references were not given. This was an early event in the debate in Britain about human experimentation. The debate excited much interest in both the lay and medical press and led eventually to the establishment of local medical research ethics committees.

The reasons why I chose to write on this subject were several: firstly, several of my postgraduate students, especially whenever I mentioned recent supposed medical advances, told me about unethical experiments that they had personally observed in British hospitals in which they were either junior staff or attending courses. Some told me of their dilemma whether or not to take an active role, or even a passive one, in persuading a patient to volunteer, knowing that non-cooperation might jeopardise their careers. For many

years as a background to my tutorials for the MRCP I had spent hours in the Royal Society of Medicine library scanning journals in which experiments in humans were described that seemed to be unethical and sometimes illegal.

A further concern was that promotion in teaching hospitals depended primarily not on clinical or teaching ability but on published work. As Beecher wrote, "Every young man knows that he will never be promoted unless he has proved himself as an investigator." So whenever I read an account of an unethical experiment I wrote a letter to the journal protesting, often as not to have it rejected. Medical research had become sacrosanct, based on the dubious dogma that its continuation must be the prime concern of teaching hospitals.

#### Press reactions

Most of the popular press reported the article with banner headlines and there were many letters from lay people and doctors either condemning or congratulat-

Spiegl's collection. They form part of a "Spieglers" entertainment—The Medical Muse: Songs, Verse, and Prose for Doctors and Their Patients.

The pictures in the

article are from Fritz

London NW3 1AX M H Pappworth, MD, retired

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ing me. The oddest contribution was a letter to the Guardian from Professor Sir John McMichael claiming that none of the 14 experiments described had been done in his hospital. The editor published my reply stating that, possibly unknown to Sir John, half of them had been done in the Hammersmith Hospital. A BMJ editorial stated, "There has been for some time public disquiet and uneasiness about investigations carried out in hospitals which have not always been in the interests of the subject of the investigation." "Undoubtedly many investigations have been harmful to patients, even if only temporarily." "We could add other similar examples, including those given by Dr Pappworth, to indicate that the physician's human obligations to his patients are sometimes abused."

I did an Independent Television programme with Dr Charles Fletcher and asked him for his opinion on a study in which 43 diabetic patients, including children and those with complications, had had their insulin deliberately withheld so that they became comatose, and then liver, and some renal, biopsies had been done. His reply—"The person was young and enthusiastic at the time and should be forgiven"—hit the headlines of the national press the next day.

#### **Royal College of Physicians**

In November 1965 Professor DM Laurence and Professor AC Dornhorst together with Sir Francis Avery Jones wrote a long letter to the president of the Royal College of Physicians (Lord Rosenheim) emphasising the problems of research in humans. They quoted Beecher and the public reprimand given by the US Surgeon General to some doctors from the Sloan Kettering Cancer Research Institute who had injected live cancer cells into a group of patients with advanced cancer and a control group (mainly prison inmates of a state penitentiary), amounting to over 400 subjects in all. In addition they had injected the same material into 19 elderly people with chronic illnesses without any explanation or consent. 56

Lord Rosenheim wrote in reply "The topic has been discussed on many occasions, the last was at a conference of the Presidents of all the Royal Colleges. It is clearly a responsibility to the public which cannot be shirked." A working party was set up and made recommendations in 1967 but these were not made public until 1973. Unsolicited, Sir Francis Avery Jones wrote to me, "I would like this opportunity personally to say how very much I appreciate the effort you have made in recent years to focus attention on this very important subject.... You did a very good job in highlighting the subject and I am sure that others think so too."

In 1984 the Royal College of Physicians issued new guidelines and in 1985 a 22 member committee was set up; it published an excellent 40 page report in January 1990. The new president wrote, "In 1967 the RCP recommended that research involving patients and normal subjects should undergo ethical review. This led to the establishment of local Research Ethics Committees. The college feels that it has now become necessary to review and update the Guidelines. They deliberately refrained from dictating a right solution." (Nevertheless, why had it taken so long to issue such a forthright document?)

#### Why I wrote the book

I met Sir Victor Gollancz at a party late in 1962, when he asked me to expand my article into a book, but he gave me a time limit. I was very busy, my manuscript was hastily prepared, and he did not like it. Unfortunately he did not employ a literary editor, who could have helped, and hence amicably the proposal

was dropped. Nevertheless, I increasingly determined to get such a book published. Neither financial gain nor self advertisement were the motives, as some cynics suggested; indeed I spent much of my own and my secretary's time in preparing the manuscript and was eager to defend myself against any vilification. My solicitor, after reading my revised manuscript, advised me to reread it carefully—a laborious task—and check the accuracy of all the quoted articles to ensure that the summaries were correct.

The difficulty then was to find a willing publisher. Each of four in turn kept the manuscript for several months, and, after consulting one of the two legal firms specialising in libel, decided not to publish.

A fifth publisher, one of whose directors was a neighbour of mine, expressed interest, but after deliberating for over six months his colleagues decided not to go ahead. I then approached another acquaintance who was the senior director of Routledge, and he agreed to publish it. The book finally appeared in 1967,\* and was to encounter criticism in both the press and parliament that the most recent studies described had taken place several years before. But that was entirely due to the time lag in getting it published.

I was amazed to get telephone calls at different times from three men claiming to be senior physicians, all telling me that they knew the details of the proposed publication and urging me "for the good of the profession" to withdraw the manuscript. None of them would give his name or say how and why he had read the manuscript.

Random House intially agreed to publish the book in the United States but changed its mind when, on the advice of my lawyer, I refused their demand to sign a covenant stating that I would be responsible for any legal damages and costs. The Beacon Press of Boston then published the American hardback and paperback editions.

## Codes

Many lay people err in thinking that all medical graduates have to take the Hippocratic oath. But that has not occurred for over 30 years, and in any case it needs altering and updating, something which I myself attempted. But let us go back several years before I published my book.

In 1947 after the trial of over 200 doctors concerned in infamous experiments, including leading doctors from Germany and Austria, the Nuremburg Code was formulated.1011 A laboratory technician, J A Tolly, each week for 10 weeks sent postcards containing the 10 rules of the code to the Minister of Health, leading newspapers, medical journals, and many members of parliament, asking "Will the Minister give a clear public undertaking that the 10 articles will apply to all medical experiments on patients in the NHS?" His efforts were unrewarded, but in 1952 the World Medical Association formulated a new code (which was updated 10 years later). Several British doctors objected to this on the grounds that it would impose undue restrictions on research, but the code was updated again in 1964 and became known as the Declaration of Helsinki.12 This was the year that the American Medical Association refused to endorse any of the codes, a leading physician claiming that it would wipe out experimental medicine and would make life very arduous legally for researchers. Conversely, the High Court judge and physician Sir Roger Ormrod stated, "The primary function of a professional code of ethics is to adjust the balance of power so as to protect the patient or client against the practitioner who has the immense advantage derived from knowledge and experience.... A secondary, but no less important, function of codes of ethics is to protect the main body

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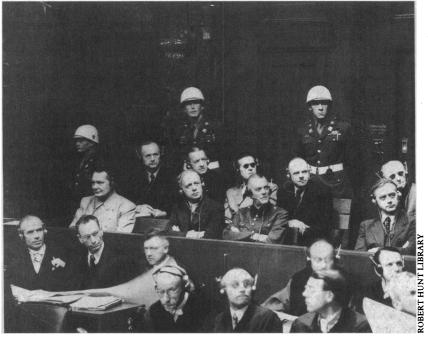
of practitioners, who comply with the provisions, against exploitation by the black sheep who are prepared to defy them."<sup>13</sup>

We now have to consider the role of two other official bodies in Britain. In 1953 the Medical Research Council issued memorandum 649, which dealt with the ethics of experimentation on humans but did not emphasise the details of informed consent. A much more strongly worded memorandum, indicating that the previous one had been ineffective, was issued in 1964.

As to the General Medical Council, according to a previous president its prime purpose is not the protection of doctors but of the public. In a letter to World Medicine I asked why the GMC had not taken action against some doctors named in my book, and why it had not publicly condemned the use of hospital patients for experimentation without their consent.14 When the South Place Ethical Society wrote to the General Medical Council on this matter its reply was, "The Council [is] not empowered to deal with matters of professional conduct which, though they may be open to criticism, do not raise the question of infamous misconduct.... The Council has not in fact received any complaint or information concerning any of the matters described in Dr Pappworth's book. . . . If your society wishes to bring a complaint that the doctors had been guilty of infamous conduct in a professional respect you are open to do so. It would be necessary for such complaints to be supported by one or more statutory declarations, and to identify the doctors concerned and provide evidence of the matters complained of." In a letter to me dated 17 November 1972 the GMC wrote, "If you considered the matters described in your book raised a question of serious professional misconduct then it is up to you to formulate a complaint. The contents of your book did not appear to be appropriate for the Council to take disciplinary proceedings." So much for the GMC's "protection of the public."

#### **Parliament**

From the mid-1950s onwards there was a series of parliamentary questions and answers about human experimentation. Thus in 1955 in answer to a question



The Nuremburg trials resulted in a code for medical experiments that was later updated to become the Declaration of Helsinki

about an experiment done in a Bristol hospital Mr Iain MacLeod, then Minister of Health, replied, "Only the clinicians in charge could say what is right and proper. It would be entirely improper for me to try to lay down what ethical principles should govern the conduct of professionals in the work they do in hospitals. I am absolutely convinced it would be quite wrong for the Minister to issue directions on this matter that is essentially one of medical ethics."

In 1958 the health minister, Mr Derek Walker-Smith, was asked concerning experiments done in London on mentally defective people and replied, "Investigations of this kind involve ethical matters which are not susceptible to control by leglislation." In 1962 the minister, Mr Enoch Powell, was asked under what circumstances experiments were permitted in NHS hospitals and to what extent they were carried out without consent. He replied, "Guidance was given to all hospital authorities in 1959. I have no reason to suppose that they are not generally observed."

In 1967, soon after the publication of my book, three MPs at various times and independently called for a public inquiry. On behalf of the government Mr Allison gave the following replies on different occasions: (a) "Allegations that doctors in the UK have carried out unauthorised experiments on NHS patients are not based on facts"; (b) "Evidence is lacking in the cases brought to the attention of the Department and the author has not been prepared to support them"; (c)"The allegations cannot be grounds on which the apparatus of public scrutiny should be brought into play. They have been promptly denied by hospital authorities"; (d) "The medical profession for generations has been guided by strict codes"; (e) "Allegations of experiments on cancer patients in the USA may be true or not but they have no parallel in Britain." With regard to the last statement, I draw attention to research I had summarised in which a 75 year old "moribund" man with general paresis and bowel cancer with metastases had been subjected to a study which could not possibly have helped him.15

My supposed lack of cooperation with the Ministry is based on a visit I had had from an official from the Department of Public Prosecutions, whose only demand had been that I name the person responsible for the experiment (on page 26 of my book) in which eight patients with peptic ulcer and haemorrhage had been submitted to lumbar aortography under the supposition that it was a routine investigation of peptic ulcer. Three patients had died as a direct consequence of the experiment, and the official pointed out that a named person would be liable to prosecution for manslaughter. That study was the only one in which I did not name names. On the advice of my lawyer I had refused to give these, which had been given to me by one of my students who later became a professor of medicine and were corroborated by another who had held a junior post in the radiology department of that hospital.

In answer to a question in 1967 Mr Snow, a parliamentary under secretary, laid great emphasis on the fact that over half the experiments I described had taken place in the United States. But he then admitted that when he read on a very early page of *Human Guinea Pigs* my likening some unamed British research workers to Nazis he had thrown the book away and declined to read it further. In the *Daily Telegraph* of 21 June 1967 Peter Simple wrote, "What sort of an argument is this? Mr Snow's interest far from lapsing should have been greatly intensified."

In a House of Lords debate on 25 January 1973 on the government bill on the reorganisation of the NHS<sup>16</sup> Lord Beaumont proposed an amendment to make medical ethical committees a statutory obligation for all NHS hospitals in which studies on patients were being done, stating that at least a quarter of the committee's members should not be doctors, paramedical workers, or anybody else employed in the NHS. Lord Strabolgi, who seconded the amendment, said that there had been demands "in the other place" for an inquiry into allegations about clinical experiments, but these had been turned down on three occasions. Opposing the amendment on the grounds of the impossibility of defining "experiment," Lord Platt, who was then president of the Royal College of Physicians, added, "In most hospitals where there are active investigating departments there is now an ethical committee. I [have no] objection to there being written into this Bill some recommendation that there should be an ethical committee, whose business it would be to meet from time to time and consider any major investigation which was brought to their notice. I doubt whether you can go further than that." He also stated, "I know that experiments have been done in hospitals which I would not have done, but which have turned out to be completely justified by experience. The view of Lord Brock, the president of the Royal College of Surgeons, was that "The provision of these ethical committees is not a suitable subject for legislation. We should leave things as they are and trust in the good sense and responsibility of the doctors.

Lord Vivien supported the amendment, saying that though *Human Guinea Pigs* was not a popular book with the medical profession, the allegations could be investigated if the amendment were accepted. Lord Aberdare on behalf of the government opposed it and said, "I noticed that the cases cited in this book were collected over a long period and from a number of countries other than the United Kingdom. Although in the past unethical experiments may have been carried out, I am sure that under present arrangements the opportunity for further similar unethical procedures is negligible." The amendment was not carried.

#### Reaction of some doctors

There is strong evidence that few doctors have read my book. Thus when I addressed over 100 staff of the Hammersmith Hospital I asked how many had read my book and only two raised a hand. A few privately assured me on other occasions that they had never done any unethical work, but they became speechless when I told them that their names were in my book. A professor of medicine boasted that no such work had ever been done in his medical school and was surprised when I told him that his own senior lecturer (later himself a professor) was mentioned several times.

On 4 February 1972 the Radio Times published an interview with me on human experiments. Dr Charles Fletcher subsequently had a letter published in that journal in which he stated, "How easily a long interview by an obsessional doctor with a special bone to pick with his colleagues can mislead. A very few doctors have occasionally abused their patients' trust and used them for research without their free consent. This no longer happens because of their strict control. Pappworth is to be commended for the part he has played in getting ethical committees instituted. He is to be condemned for his continued public attacks on his professional colleagues."

My opinion remains that those who dirty the linen and not those who wash it should be criticised. Some do not wash dirty linen in public or in private and the dirt is merely left to accumulate until it stinks.

One of the most influential writers on medical ethics, Professor H K Beecher of Harvard, the author of an important book, 'attended a conference in 1964 on the problems and complexities of clinical research. His complaint of "breaches of ethical conduct in experiments which are by no means rare but are almost universal" produced a vitriolic attack on his good faith from some of the audience. He was so shocked that he approached the editor of the *New England Journal of Medicine*, who advised him to summarise some of the objectionable experiments. The published article, which I had helped to compile, summarised 22 experiments including seven instances supplied by me. Nevertheless his account was written in very technical language and no names or journal references were given; he told me that this had been done on legal grounds given that the investigators might be liable to criminal proceedings. I believe that giving names and references has, at least in small measure, acted as a deterrent.

#### Limitations of ethical committees

The BMJ has recently had an excellent editorial on the shortcomings of ethical committees.<sup>17</sup> Neither the committees nor their decisions have any legal status, and their establishment is not mandatory.

Their performance is variable and influenced by their composition, the procedures followed, the time spent on deliberations, the frequency of their meetings, which protocols must be submitted, and which submissions should be allowed. Some members, though unhappy about the work of some colleagues, may take pride that it may possibly bring prestige to their hospital. There is also the possibility of collusion—if you approve my work I will approve yours.

The effectiveness of such committees in Britain has never been investigated or monitored, sometimes because the members refuse to act as policemen. A medicolegal expert has written, "The aim of getting consent of an ethical committee for an experimental procedure is to ensure the patients' interests. It should not be a purely procedural and defensive step." 18

Most importantly, ethical committees have no sanction of instituting penalties against those who ignore or act beyond the limits of an agreed protocol. The Royal College of Physicians' report admits, "Plainly the investigator who bypasses or ignores their recommendations creates a potentially serious problem which could make him vulnerable to professional discipline or even legal procedures." In Australia insurance companies refuse to give cover to doctors who engage in research on patients unless their work has been submitted to and agreed by an ethical committee. Yet Dr Richard Nicholson, editor of the Bulletin of the Institute of Medical Ethics, has stated that one in nine of a large number of committees investigated in the United Kingdom conducted their procedures entirely by letter or phone.19

## **Editorial responsibility**

Eighteen years ago the journal Clinical Science listed eight rules for editors to bear in mind when they were dealing with articles reporting experiments on humans. Yet how many medical editors abide by those rules? The Royal College of Physicians' guidelines state, "It is desirable that authors indicate their research has been approved by an ethical committee." Why merely "desirable"?

Beecher wrote to me that "The Law-Medical Institute of Boston questioned the editors of 61 medical journals produced in the United States of America asking, 'Would you have concern for the social obligations of clinical research activities as part of your editorial responsibility?' Seventeen editors had replied 'No." Elsewhere he stated, "How many would carry out experiments if they knew that they would not be published? Valuable data which has been improperly obtained should not be published even with stern editorial comment." I believe that the time has come

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to tighten all these aspects up. Researchers themselves, their units, hospital ethics committees, and editors of medical journals all have a vital role—otherwise legal sanctions will inevitably raise their heads again.

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## Turning the BMA into print

Gordon Macpherson

BMA members attending their first annual representative meeting must wonder how decisions can ever emerge from such apparent confusion. One man skilled at turning the turbulence of the BMA's democratic process into the order of the printed page has just completed over 40 years of continuous attendances at ARMs. Lawrie Wootton, until recently senior partner at T A Reed, a distinguished firm of parliamentary and court reporters, signed off his final set of transcripts for the BMA at Bournemouth this summer. Gordon Macpherson, who retired as deputy editor of the BMJ in October, talked to him about his experiences.

Few men can boast that they were present at the Lüneberg trial of the guards of the Belsen concentration camp, the birth of the state of Israel, the foundation of the Council of Europe at the Hague, the interrogation of spies in wartime Britain, the trial of the notorious Heath, hanged for murder, and the parliamentary debates on the founding of the NHS. Lawrie Wootton recorded all these events in his 200 words a minute shorthand. Ironically, his path to reporting the more mundane occasions of BMA meetings started during the war at a courtmartial of an army medical officer. The transcript of that trial was admired by the then senior partner of T A Reed, who when the war was over invited Mr Wootton to join his team of parliamentary and law court reporters.

Acceptance of that invitation led to a worldwide career producing verbatim reports of conferences, parliament, the law courts, Guildhall dinners, the General Medical Council-where he recorded the disciplinary hearing of the court martialled medical officer-meetings of the BMA, and conferences of other professional associations. He could have covered the trials of the top Nazis at Nüremberg but, admitting to a youthful "lack of a sense of history," he was more anxious to get demobilised than record the courtroom drama that marked the end of Hitler's Germany.

After two years' wartime service in the Royal Artillery Lawrie Wootton was called to the War Office and transferred to the judge advocate's department to apply his verbatim reporting skills acquired working for a local newspaper. Apart from courtmartials, he recorded the interrogation of several spies, doing so behind a screen so that "the interrogators and defendants weren't distracted by my pen scratching." Transcribing question and answer after question

and answer, "you become a bit like a machine," he said. The information "went in your ear, through your brain, and down your arm, and someone once described such verbatim reporting as one of the finest examples of coordination of hearing, brain, and hand."

T A Reed was, he said, always reckoned to be the Rolls-Royce reporting service—only about 100 reporters could do what he did-and the firm covered all the technical conferences, "where the words with more than four letters were used." Though he transcribed his notes as soon as practicable, Mr Wootton often had up to six meetings "in my shorthand books' at one time and this may have included the BMA, the British Dental Association, the architects, the church, and an international commodity conference. "I've sometimes had to read my notes seven years after a case and as soon as I started to read them I could see the court and the people involved."

#### 250 000 Words

He has always been meticulous about names, and as a double check of his transcripts he may borrow the notes of those speakers who use them. Such skills were essential for the BMA's annual meeting, when around 400 pages of transcript—approximately 250 000 words -were produced. He could not do such a concentrated task on his own and was helped by three or four colleagues, each doing 15 minute reporting stints before breaking to type out the shorthand record. Thus, as with parliament, the complete record was to hand within an hour of each day's session ending, an invaluable service to those of us who had to prepare a subedited report for the next week's BMJ. Thirty years ago his reports on an annual meeting would fill 66 pages of the journal-over 60 000 words-but the style of presentation has changed as readership tastes have changed and the pressure on space has greatly increased. In his final ARM Lawrie Wootton's 250 000 words were condensed by Scrutator to around 20 000.

His reliability was evident early on from a request by The Times to accompany Aneurin Bevan during his speech making tours during the launching of the NHS. The Minister of Health had complained of being regularly misreported. "A superb speaker, he never made notes, and The Times wanted an accurate record of what he said," commented Mr Wootton. They would have had that, without doubt. Throughout his professional life his reports were never successfully challenged. Nor was he ever asked to doctor a report,

British Medical Journal, London WC1H 9JR Gordon Macpherson, MB, former deputy editor

Br Med 7 1990;301:1460-2